

December 16, 2011

Dear Tracy and Charlie:

Below is some information that explains APF's role and resources for helping people with pain that I've been able to offer with the limited turnaround time during an extremely busy week. Responses to your reference questions are at the end.

It is clear to me from your line of questioning (wish you had sent questions in advance as I requested) that you had already constructed a story about APF before speaking with APF and were looking for more information to fit your story line. This does not seem to be the best way to get to the truth nor to conduct a fair and balanced investigation. I hope that the information below is useful to you in accurately conveying the work of APF and our relationship to our funders.

It is also clear to me from your line of questioning and the previous stories that you have written that your story is meant show a harmful influence of corporate funding on APF's work. As mentioned in our conversation, we develop annual work plans and funding plans based on the needs expressed by the people we serve. We then seek funding to meet those needs and plans. We have a process and a code of ethics (<http://www.painfoundation.org/about/code-of-ethics.pdf>) that we implement and enforce to protect us from the influence of any funder. This Code was devised to avoid any possibility of influence of the type you imply.

Our sole interest is in improving the lives of people affected by pain. As a small organization addressing an enormous public health problem with a huge population to serve, we are grateful for the support we receive to do the work we do. People living with pain have few advocates and few resources to turn to, and with the escalating amount of negative attention misdirected at the people we help, the need to speak out is even greater. With limited resources we work tirelessly to help people with pain who virtually have no champions in the care and policy arenas and who are often weakened and isolated as a result of their illness; their social, emotional, and financial stresses; and systems that make it difficult to get care. If there is a battle to be fought in the media, it should be aimed at helping people living with pain to get better care.

Please read and consider the following information as you proceed with production of your story and if you have further questions, please let me know.

- I want to make you aware of, if you are not already, the IOM report that came out in June 2011 entitled: *Relieving Pain In America: A Blueprint for Transforming Prevention, Care, Education, and Research*. <http://www.iom.edu/Reports/2011/Relieving-Pain-in-America-A-Blueprint-for-Transforming-Prevention-Care-Education-Research.aspx>. This report describes the extent of the problem of pain (116 million people) and the critical need for improved care, the deplorable state of professional understanding and skills for treating pain and the

significant need to expand research in pain and its treatment. This report illustrates the *raison d'être* of American Pain Foundation. We have a constant need to expand and diversify our funding if we are going to be able to make progress in helping people affected by pain. We are mission driven with the sole purpose of improving the lives of those affected by pain through education, advocacy and support.

- Statistics are empty without viewing the faces and stories of the people who live them. The better portrayal of why we exist is illustrated in the thousands of requests we get for help in finding pain care, in dealing with doctors and clinics refusing to care, and in not understanding basic information about pain conditions and treatment options. We hear from people caught in a variety of circumstances that challenge their ability to get care. Here are three examples from the last few days. One is reported in the **Seattle Times** this week and two are e-mails received this week at the APF.

This article in the Seattle Times is one of three that reveals the unintended negative consequences of state policy and practice policy on people living with pain:

http://seattletimes.nwsourc.com/html/localnews/2016994769_silent12.html.

Here is an e-mail we received on Tuesday from a woman in PA who has been on the same medication for 10 years and was told that a photocopy had to be taken of their driver's license when picking up meds. She had justifiable privacy concern about the practice:

My name is Mary XXXX. My husband, John has been in contact with you in reference to CVS and their policy on narcotic scripts. I would like to express my heartfelt gratitude to you on all your time and help with regard to this matter.

It is such a positive, confident feeling that as a pain patient, I have a place like the American Pain Foundation to go to for advice and support.

Joseph went to our usual CVS in ZZZZZZZ, PA and spoke to the pharmacy manager, whom we know quite well. He has always been a big help to me. He told us that CVS now requires an ID to be shown to get a narcotic script as well as an ID for the person either picking up or dropping off the script. But, he knew nothing regarding the copying of a license. He also told us that he would never do that, especially since I have been on narcotics since 2004. We then followed your advice and spoke to the CVS corporate office as you suggested. They listened to our complaint and kept us waiting until they could confirm their policy. The bottom line was that there is no policy regarding taking a copy of the license and that the Effort store should not have taken a copy. They told Joe that the district manager would give us a call.

We received an email from the district manager apologizing for copying the licenses. John also told the corporate office that he would be returning to that store in order to get the copies back. Here is a quote from the district manager's email, "With the increased instances of fraudulent narcotic prescriptions, the DEA is now requesting that we obtain a photo ID from everyone presenting a narcotic prescription. We are to make

a record of who drops it off. My store should not be copying your license and I apologize if they have done so. I have reviewed the expectation with them and there is no need to copy your license."

Earlier today, I spoke to the district manager. She again apologized for the copying. At times, even if she was asked by a store for a copy of her own license, she would refuse. I also explained that I have no problem showing an ID, but there will not be an available picture in the event that someone stole the copies and would then know where I live. She was gracious and certainly understood our complaint.

Thank you from the bottom of my heart for helping us. I was so upset. It's difficult enough to deal with chronic pain. I do not need to deal with additional problems. Even though I and many other people struggle with chronic pain every day, it doesn't mean that we are "labeled" and have no rights. Your help in this matter was very comforting to me. It is reassuring to know that there are people in this world, like you and the American Pain Foundation, who care and understand our struggles.

May you and your family have a wonderful holiday season!

Sincerely yours,
Mary XXXX

Here is another e-mail received this week which is a thank you to the APF from someone who found support and information that relieved her sense of isolation and hopelessness when learning of her disease:

Dear APF:

....because the APF website, especially PainAid, was such a huge resource & support to me when I was first diagnosed with Complex Regional Pain Syndrome. It helped me find alternative treatment options (like spinal cord stimulation). I am allergic to nearly all opiate pain medication & I failed a number of other treatment modalities (epidural injections, numerous medications, acupuncture, physical therapy, surgery, etc.) so finding another treatment option was critical. At the time of my diagnosis, I was extremely depressed & I felt very isolated, as I did not know anyone who also have severe chronic pain. It was a relief to have a place to go & vent my frustrations with my condition, treatment failures, the Worker's Comp system, etc. & get advice from people who had dealt with the same struggles.

After my condition stabilized with medication & spinal cord stimulation, I spent as much time as I could on the website providing support & information to other people with chronic pain, especially those considering spinal cord stimulation. I have received countless emails from people who read my story on the APF website & have contacted me directly. I have kept in contact with a number of other people I met through the APF

website for several years. I can't tell you how great it is to talk to people who know exactly what it's like to live with chronic pain every second of every day. The emotional & practical support I've received has been invaluable.

I think that helping others has been part of the rehabilitation process for me. It forces me to keep my condition in perspective & keeps me from feeling sorry for myself. I currently work as a county home care social worker in San Jose, CA, so I have the opportunity to help people with chronic pain every day. ...

Sincerely,
Emily ZZZZZZ

I do not know how or where people with pain will get support of this kind without APF being there for them. I also do not know how APF can be there for them without the funding that we receive from many sources including corporations.

- One of the first question areas you addressed was the recent CDC report on opioid misuse/abuse/overdoses. I mentioned that I had questions and concerns about that report. We are working on a request to the CDC to talk about that report, its content and tone. Some of our concerns are contained in the following two responses to this report. This is genuine concern for representing data and issues clearly and fairly. Another concern is that one of the authors of the recently released CDC report is a member of an organization with explicit practice beliefs. See the following for an expression of the type of concerns we have with the recent CDC report:
 - <http://thehill.com/blogs/congress-blog/healthcare/192321-a-call-to-stop?page=1#comments>
 - <http://pain-topics.org/pdf/e-Briefing-Vol3-No1-2008.pdf#search='statistics on opioid addiction'>.
- We all know that there has been an elevated concern about the safe use of opioids. There is now widespread agreement that practitioners need to have greater understanding and skills in assessing and managing the risks of opioid medications. Our statement in May 2011 regarding opioid therapy expresses this position.
<http://www.painfoundation.org/about/position-statements/opioids-for-persistent-pain.html>. This was produced to reflect the growing awareness for increased attention to risk assessment and safety with the use of opioids. Also, as early as 2008, we produced key recommendations regarding opioid therapy in:
<http://www.painfoundation.org/learn/publications/files/KOLKeyProceedings.pdf>. See pages 5/6 especially. Knowledge and practice understanding is constantly changing. Please see two recent tools developed for patient and prescribers to help promote safety in the use of opioid therapy:
 - <http://www.painfoundation.org/learn/publications/files/cot-worksheet.pdf>
 - <http://www.painfoundation.org/learn/publications/files/cot-dos-donts.pdf>

- One of the other questions you had concerned the Senate Hearing that Dr. Campbell testified at. He was not representing APF in that testimony. Also, the hearing was about Oxycontin. I recollect that the title was something like “Oxycontin and other defective products.” I recollect that Senator/Doctor Coburn stated at the beginning of that hearing that as a doctor he thought the subject of the hearing was inappropriate. He stated that he and many of his colleagues prescribe this medicine and something to the effect that it’s not the medicine that is defective but the one who misuses the medicine----whether it’s the prescriber or the patient or the abuser.

So much of your questioning focuses on opioids but most of our advocacy work, in addition to our advocacy for individuals, in the last five years has been about passing the Military Pain Bill, the Veteran’s Pain Bill and the National Pain Care Policy Act all of which have the similar components of: 1) Improving pain care; 2) training and educating practitioners to provide appropriate assessment and treatment of pain; and 3) increasing investment in pain research. Pain is complex and affects individuals in significantly different ways. There is no single treatment answer for this complexity and the individual responses to this complexity. Although there is significant media and policy attention to opioid therapy, most of our education and advocacy work focuses on the broad array of treatment concerns.

- What about the 7+ million people who are living with fibromyalgia many who are still told that since there is no definitive diagnostic test for the condition, it must all be in your head?
- What about the one million people a year who contract shingles who did not know of or did not have access to the shingles vaccine which has a very high prevention quotient for both shingles and post herpetic neuralgia?
- What about the millions of older adults who suffer with arthritis and do not have an adequate understanding of the limitations and risks of over the counter medications?
- What about 5% of women between the ages of 18 and 65 who experience headache 15 or more days per month over the course of a year?

These scenarios have nothing to do with opioid therapy and yet affect an extraordinary number of people with complex pain care challenges that the APF engages in.

APF IS COMMITTED TO SPEAKING OUT FOR PERSONS LIVING WITH PAIN TO MAKE SURE THAT THEY ARE NOT FORGOTTEN AND NOT ABANDONED.

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WRITTEN RESPONSES TO PROPUBLICA'S QUESTIONS

ProPublica: In APF's treatment guide for patients

(<http://www.painfoundation.org/learn/publications/files/TreatmentOptions2006.pdf>), there is a lengthy discussion about the risks and dangers of NSAIDs. "Whenever an NSAID is taken for pain, it is prudent to use the lowest effective dose and to stop the therapy unless it is clearly needed over time. Though NSAIDs are commonly used medications, they do have dangers and must be used appropriately." (P. 11) The side effects of opioids, on the other hand, are portrayed as minor. "Obviously, it is very important to get the facts about these effective and powerful pain medicines because their under-use has been responsible for much unnecessary suffering. Those affected by pain, providers, patients and family alike, need to be well-informed to be sure that myths and misunderstandings do not get in the way of effective pain control." (P. 12). Does the guide provide a fair balance on the risks and benefits of both classes of drugs?

Rowe: *Treatment Options: A Guide for People Living with Pain* is a book that was written in 2005 by a group of highly respected experts in the various treatment modalities covered in the Book. The information about side effects for non-opioids covers about ¾ of a page. The information about side effects of opioids, including tolerance, physical dependence and addiction covers two pages. For the time that the book was written, the coverage for side effects is fair and balanced for both classes of drugs. A new edition of the book will make numerous updates about all of the treatment modalities.

ProPublica: The reporter's guide says in at least five places that the risk of addiction from opioids is low. Given the NIDA statement that the risk of addiction isn't known and can range from 3% to 40%, doesn't APF's language overstate the facts?

Rowe: Please provide a reference for the NIDA statement. I could not find one.

All of our statements about the risk of addiction in this guide, and in our other publications, include statements like..."...the risk is small when these medicines are properly prescribed and taken as directed." We stand by this statement. This guide also lists the risks associated with potential abuse, including personal or family history of abuse, and the potential consequences of abuse: "When abused—that is, taken by someone other than the patient for whom the medication as prescribed, or taken in a manner or dosage other than what was prescribed—prescription medications can produce serious adverse health effects and can lead to addiction, overdose and even death." P.31.

ProPublica: The same guide states "Less than 1% of children treated with opioids become addicted." As a reference, APF cites Foley KM. (1996) Controlling the pain of cancer. *Sci Am*, 275(3):164-165. Our review of this article found no mention of children or risks of addiction. We were unable to find this statistic in searching literature more broadly. Is that an inaccurate reference?

Rowe: I am still researching that reference. The same statement and citation appear in Childcancerpain.org under “Myths.”

<http://www.childcancerpain.org/frameset.cfm?content=barr01>

ProPublica: Research suggests that studies into the effectiveness of opioids for chronic pain are limited and often exclude those whose histories suggest they may become addicted. Why are those not mentioned in APF’s publications or statements?

Rowe: People who have substance abuse problems and pain deserve to be treated for their pain as much as anyone else using whatever options are most effective and with careful risk management. There is a far greater need to monitor and reassess but failure to treat their pain with consideration of all treatment options is inappropriate.

ProPublica: In the Pain Management Today e-newsletter this year, Dr. Kuritzky recommends opioids for knee or hip osteoarthritis. Here is the Cochrane review from 2009: “The small to moderate beneficial effects of nontramadol opioids are outweighed by large increases in the risk of adverse events. Nontramadol opioids should therefore not be routinely used, even if osteoarthritic pain is severe.” How can you reconcile Dr. Kuritzky’s position with that of Cochrane?

Rowe: Two studies were published after the Cochrane paper, Corsinovi et al (2009) and Hatrick, Feb 2009, were cited in the Kuritzky article. The Cochrane search went up to July 28, 2008. Corsinovi et al, for example, states that “opioid combined therapy may represent an effective and safe option for the treatment of uncontrolled moderate to severe OA pain in older women.”

ProPublica: Coincidentally (we just saw it after our conversation), New York City put out its own guide on opioid use today. It’s tone is quite different.

(<http://www.nyc.gov/html/doh/downloads/pdf/chi/chi30-4.pdf>).

Rowe: I think that there is a difference in tone but not much difference in essential safety content from our document for prescribers:

<http://www.painfoundation.org/learn/publications/files/cot-worksheet.pdf>